

Division of Services for People with Disabilities



January 1999

disABILITY NEWS NOTES &

Volume 9 Issue 1

EXCHANGING INFORMATION ABOUT THE SERVICE DELIVERY SYSTEM IN UTAH



Division Presents Seventh Annual Ila Marie Goodey Awards by Renae Taylor, Quality Enhancement Director

The Division of Services for People with Disabilities named **North Eastern Services** and **TKJ, Inc.** as the recipients of the 7th annual Ila Marie Goodey Awards for *high quality and innovative efforts in behalf of Utah's citizens with disabilities*. **Sue Geary**, Division Director, made the presentations at the awards luncheon held at the Olympus Hotel in Salt Lake City on November 30, 1998. She was joined in the presentations by **Robin Arnold-Williams**, Executive Director of the Department of Human Services and **Jay Peck**, Division Board Chair, **Terry Buckner**, **Kris Fawson**, and **Jeffrey Swinton** Board Members, and **Jon Belnap**, Chair of the Consumer Advisory Council.

Wayne Crabb, President of North Eastern Services (NES), was presented the award for *organizational commitment in supporting people to realize personal outcomes*. NES, a non-profit organization, has offered residential supports in Logan, Utah County, and Roosevelt for the past fifteen years. According to Mr. Crabb, the operation remained the same until 1995 when NES boldly restructured. Fresh ideas combined with new management resulted in a strong

organizational commitment to helping people achieve a high quality of life.

TKJ, Inc. was presented with their second Ila Marie Goodey Award which was conferred this year *for their pursuit of excellence in supporting people to realize personal outcomes*. **Terry Jensen**, President, accepted the award for TKJ which is a private, non-profit agency that provides supports and services to people with disabilities living in the Salt Lake County and Price areas. TKJ, Inc. has a long-term commitment in supporting people with disabilities to achieve personal outcomes.

This award is named after **Dr. Ila Marie Goodey**, a psychologist formerly with the University of Utah. Dr. Goodey has been recognized locally and nationally for many years as a passionate advocate for people with disabilities. Dr. Goodey has been described as representing "the ideal of selfless service to others with uncompromising insistence on the right of all people to experience a high quality of life, especially those who are unable to fully represent themselves."

(l to r) Wayne Crabb, Sue Geary

(l to r) Terry Jensen, Sue Geary

Climbing Towards SELF-DETERMINATION

by B. J. Bertrand, Training Specialist

This is an exciting time to be involved in the support system for people with disabilities, due to a growing awareness of and concern for individuals' needs and dreams. In Utah, we have been steadily trekking up the mountain that leads to self-determination for people with developmental disabilities. Self-determination can be defined as having the support, experience and authority to define, choose, and achieve satisfaction in life. Notable trail markers on our path have included the use of the *Personal Outcome Measures*, developing person-centered plans and budgets, strengthening natural supports, assisting people to exercise their rights, and restructuring formal systems.

Personal Outcome Measures: A major component in supporting people with disabilities moving towards self-determination in Utah has been the focus on *personal outcome measures*. We have utilized the outcome measures in a variety of ways, including:

- ◆ As an educational tool to assist support coordinators and direct care staff to provide person-centered supports and services,
- ◆ As an assessment tool to provide needed background information to prepare for person-centered planning meetings, and
- ◆ As a quality guide to aid organizations providing supports and services that enhance quality of life. For example, in 1997, the state of Utah contracted with The Council on Quality and Leadership in Supports for People with Disabilities to utilize the *outcome measures* as our state quality enhancement review process. This partnership was developed at the request of the agencies that provide direct services.

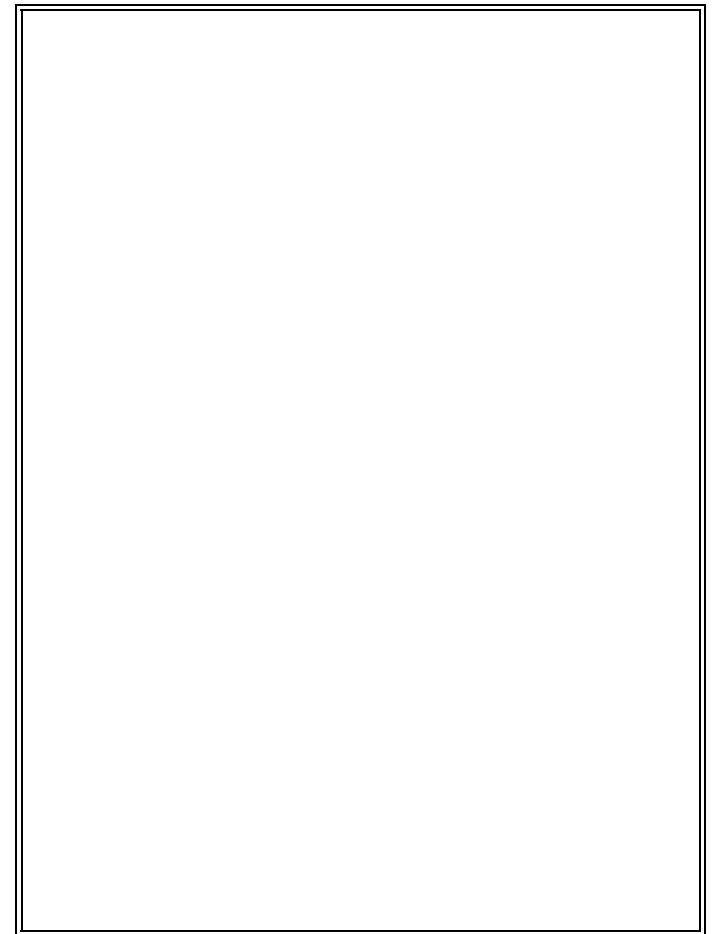
We have found that all of these usages of the *outcome measures* promote self-determined living for people with disabilities.

Person-Centered Planning and Budgeting: Another component in realizing a self-determined process is person-centered planning and budgeting. Several years ago, the Utah Division of Services for People with Disabilities began offering training and technical assistance in person-centered planning methods. The focus of person-centered planning is on the individual's capacities, talents, abilities and dreams. Person-

centered planning promotes the individual's ability to connect and participate in the community, choose a desired lifestyle, and carry out informed choices.

Training on person-centered budgeting issues has only recently begun. In 1997, Utah was awarded a Robert Wood Johnson Foundation grant to promote self-determination. As part of the grant project, Utah is experimenting with person-centered budgeting with a limited number of people receiving State-funded supports and services. Person-centered budgeting is also being used for all people with disabilities leaving the waiting list and upon their entry to services. It is expected that eventually person-centered budgets will be completed more widely throughout the state.

Strengthening Natural Supports: The development of natural supports is another essential component of promoting self-determination. The Council defines "natural support networks as groups of people whose commitment to support each other is usually lifelong. This includes family members and very close friends."



In a broader sense, natural supports may include other members of the person's community, including co-workers, neighbors, grocers, or store clerks. Nurturing and strengthening natural support networks for people with disabilities helps to ensure that their dreams and

goals can be achieved. In Utah, some of our efforts to strengthen natural supports have included:

- ◆ Increasing training opportunities for all stakeholders,
- ◆ Encouraging and supporting family-centered planning and person-centered planning,
- ◆ Supporting the practice of some provider agencies to offer cash bonuses to direct care staff for connecting people being supported with non-paid staff, and
- ◆ Establishing the Utah Map to Inclusive Child Care Project, a federal initiative to promote inclusive child care for children with disabilities.

Exercising Rights: Self-determination is a process which empowers people with disabilities to have control over their lives. Through self-determination, people receiving State services will be supported in exercising the same rights and choices and be afforded the same opportunities enjoyed by other citizens. In order to assist people with disabilities to fully exercise their rights, the Utah Division of Services for People with Disabilities has revised its policy on Human Rights. Some of the changes include the requirement that “all people with disabilities funded by the Division must have access to a Human Rights Committee” and the requirement that all agencies providing services to people with disabilities “shall develop an Agency Human Rights Plan.” The Agency Human Rights Plans require agencies to describe how they will educate, train and support people to understand and exercise their rights.

Formal Systems Restructuring: Like other major change efforts, the climb towards self-determination has required formal systems restructuring efforts. Some of the changes occurring in Utah include:

- ◆ Updating formal policies and procedures, (e.g., Human Rights Policy),
- ◆ Rewriting Medicaid Waiver regulations,
- ◆ Opening up membership on decision-making Boards and committees to include more people with disabilities and family members, and
- ◆ Committing to training and supporting people with disabilities to facilitate person-centered plans and other training activities.

As defined by **Donald Shumway** and **Thomas Nerney**, the four principles of self-determination are:

FREEDOM to plan a real life,

AUTHORITY to control a targeted amount of resources,

SUPPORT for building a life in one’s community,

RESPONSIBILITY to give back to one’s community.

In Utah, we are committed to experimenting with a variety of methods to determine how to help people lead self-determined lives. We have yet to reach the apex of self-determination for all of the people with disabilities receiving supports and services, but the trek is well underway.

Survey & Review

by **Jerry Costley**, CEO, Avatar, Inc.

Recently, the **State Quality Enhancement Team**, in conjunction with a representative of **The Council on Quality and Leadership in Supports for People with Disabilities**, performed a survey and review of our supports and services. In addition to simply performing the interviews and reporting the results, the State Quality Enhancement Team and the Council representative fully involved our organization, which made the survey a tremendous learning and planning experience. Staff were allowed to participate in interviews and in the decision making process, where the interview results are interpreted. This, in itself, was a tremendous "eye-opener" for those who participated.

However, the best part of the process was when our management team met with the official surveyors, as well as our staff who assisted them. We reviewed the results, what these results mean to our organization, and how we could incorporate them into our Quality Improvement Plan. This resulted in significant changes in our Quality Improvement Plan, which in turn led to a much better focus of our management efforts.

This is a process that all of us who participated highly recommend to all others who are working on issues of change and improvement.

Claiming My Future Clubs

by **Paul Day**
Program Specialist

The Utah Advisory Council (State Consumer Council) is announcing an exciting opportunity for consumers and others. **Claiming My Future Clubs** are being established throughout the state. These clubs will meet on a monthly basis over the next year. Some topics that could be discussed at the club meetings are:

- ◆ How to make your life dreams come true
- ◆ How to let others know what you want
- ◆ How to set goals, make plans, have fun, and manage the details of your life
- ◆ How to tell if you are getting what you want and how to change things that are not the way you want
- ◆ How to create your own support network to help you get what you want
- ◆ What leadership is...and how to become a leader in your own life
- ◆ How to get involved in your community and make it a better place for everyone

Come on your own, or invite friends, family and other supporters to the meeting if you want. Call Group Organizers to find out when a meeting will be held in your area:

Vanese Nash (801) 270-9457

. Ogden, Salt Lake, Orem/Provo

Emilee Curtis (435) 259-9400 All Sites

Jon Belnap (435) 674-2226 St. George

Troy Pope (435) 789-0001 Vernal

Please call if you need a ride, have questions, or to tell them you are coming to the meeting.

New Self and Peer Advocacy Program Started

by **S. Travis Wall & Tom Brownlee**
Project Coordinators

The **Arc of Utah** (The Arc) is developing a self and peer advocacy program for people with disabilities. The program, which is known as the **Utah Leadership Project**, will support people with disabilities in:

- ◆ Learning how to express and assert their choices and preferences.
- ◆ Learning how to be advocates and leaders on behalf of themselves and other people.
- ◆ Developing local and statewide advocacy groups.

The Project is developing a curriculum for beginning, intermediate and advanced advocacy trainings. The first training events will begin later this year. The Project is also assembling a Leadership Cabinet to oversee the Project. The Project is staffed and the Cabinet will be entirely made up of people with disabilities.

The Project is funded by a grant The Arc has with the **Division of Services for People with Disabilities**. The Arc plans to continue the Project after the grant ends. The Project is being carried out in conjunction with the **Disability Law Center** and the **Governor's Council for People with Disabilities**.

For more information about the Project, including upcoming training events and serving on the Cabinet, contact **Tom Brownlee**, Project Coordinator, at The Arc of Utah, 455 East 400 South, #202, Salt Lake City, Utah, 84111, (801) 364-5060.

"Walk Around the Clock"

by **Melinda Norton**, Assistant Director



The **Work Activity Center** is planning its annual 24-hour "Walk Around the Clock" to raise funds for educational materials and recreational opportunities. It will be held on May 7-8, 1999, at **Murray High School**. Last year's inaugural event raised more than \$13,000 and helped with recreation, Special Olympics and assistive technology. Part of this year's funds will be used to fulfill participants' dreams. Anyone interested can help by signing up to participate on a team, making a donation, and/or attending the event (977-9779).

Special Olympic Athletes
by Marjery Jorgensen



Special Olympics
Utah

Congratulations to the Utah State Developmental Center (USDC) Special Olympic Athletes!! In October, athletes from the Center participated in the 1998 Fall Sports Classic at the University of Utah. Athletes participated in aquatics and basketball skills. The Olympians brought back gold, silver and bronze medals. The athletes had a great time and especially enjoyed the generous lunch that was served.

Olympians will be gearing up for the Winter Sports Classic, which includes bowling and skiing. The Area Games were held in January and the State Games will be held in February. Thanks to the Special Olympics and to all our staff who go out of their way to make this a quality program at the Developmental Center.

**Child Care Grant for
Children with Disabilities**
by Marilyn Bown,
Program Specialist

As of January of this year, the Department of Workforce Services has child care benefits available to employed parents of children with disabilities under the age of 19 if their disability is severe enough that the cost of providing child care is greater than the cost of providing care for children without disabilities. Parents qualify at 85% of the state median income rather than 65%.

There are two kinds of benefits awarded:

- ★ A one-time grant up to \$1,000 for the providers of child care to purchase supplies, special training, equipment or modifications.
- ★ An increased rate to help cover additional costs for serving a child with a disability up to the infant care rate.

The definition of disability cuts across agencies and also includes children with health and mental health issues if, indeed, the costs of providing child care are greater than those of a typically developing child. The Division of Services for People with Disabilities acts as a clearinghouse to facilitate all necessary documents that establishes the special need. However, parents need to apply first through the Department of Workforce Services in their area.

There is a representative in each region to train support coordinators and answer questions concerning this benefit. They are:

- ★ Steve Clark Northern Region
- ★ Melody Morgan Central Region
- ★ Janet Kinder Eastern Region
- ★ Theo Judson Western Region

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PERSKE: PENCIL PORTRAITS 1971-1990 (Nashville:
Abingdon Press, 1998).

**Mattel Launches
"School Photographer
Becky®":
Barbie Doll's Friend
Who Uses A Wheelchair**

Information release from Mattel, Inc.

In September Mattel, Inc. announced the introduction of BECKY® "I'm the School Photographer!" The Barbie® doll's friend who has a disability is a photographer for her high school yearbook. Becky uses a red and silver realistically designed wheelchair and for the first time, she has a *career*. Becky also appears in a new book entitled, Barbie, The New Counselor, published by Golden Books, where she works as a camp counselor with Barbie. This emphasizes Becky's leadership abilities and sends a powerful message to kids. Last year "Share a Smile™" Becky sold out in two weeks.

Break out sessions were available so students and parents could learn more about agency services and benefits, ask questions, and familiarize themselves with how to apply for services.

Refreshments were served and drawings for prizes were held every 15 minutes. The refreshments were donated by the Weber County School District's various high schools. The prizes were donated by the members of the sponsoring Community Transition Council (CTC).

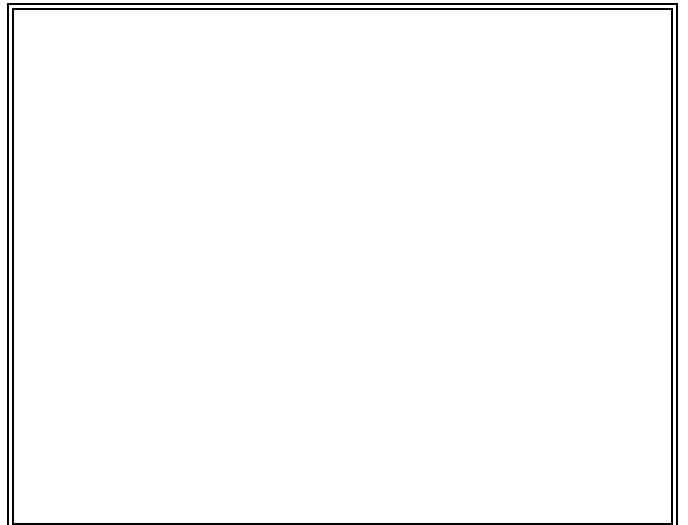
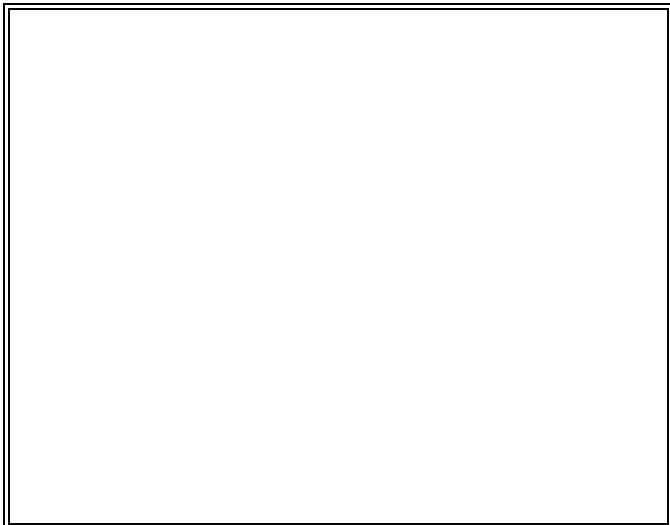
by **Leora "Lee"** Medina, Support Coordinator

"Determining Your Path for the Future" was the title of the Morgan County/Ogden City/Weber County School Districts Annual Community Transition Fair held on October 20, 1998 in North Ogden. The focus of the fair was to give transition students with disabilities, and their parents, an opportunity to meet with community agencies, service providers and institutions that can help them facilitate plans to transition from school to adult living at age 22 when they exit the school system and to address issues of community access, education, employment, independent living, and recreation leisure.

The fair was attended by over 150 students, parents, teachers, and various staff from agencies and service providers. Approximately 25 service providers and agencies were represented, participated and set up display booths, and handed out resource information.

A sincere "Thank You" to the CTC chairman, **Paul Mereola**, from the Office of Rehabilitation Services, to Weber School District; Ogden City School District; Morgan School District; and to the Ogden-Weber Applied Technology Center for the use of the Student Union Building; Department of Workforce Services; the Division of Services for People with Disabilities and all the service providers and other agencies who assisted and participated in all aspects of the fair; and to all the students and their parents for the great turnout. We look forward to next year's annual Transition Fair.

Picking Up Information at the Transition Fair

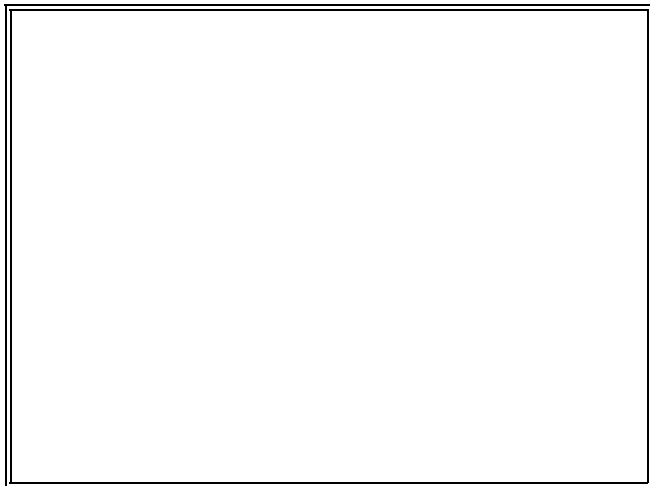


Simon Stonebraker Speaks at National QMRP* Conference

by **Janeal Jacobs**, Bethphage, Inc.

(*Qualified Mental Retardation Professional)

In recent years, people with disabilities have become more involved in informing others of their rights and how those rights should be respected. **Simon Stonebraker** is one of those people. Simon is a 26-year-old man who, for the past four years, has been training the staff of his residential provider on his rights and how they should be respected. Simon has been very successful in these trainings.



Simon Stonebraker

Within the last three years, Simon has received much attention from the national trainers of Bethphage, his residential provider. In August he was asked to assist them in a seminar at the National Qualified Mental Retardation Professional Conference in San Antonio, Texas. Simon was able to share his experiences as a trainer with people from around the nation. The message he and Bethphage shared was that there is no better person to train on his needs than himself and that idea applies to all people with disabilities. Initially, Simon was scheduled to be a guest speaker; however, as the seminar progressed, Simon became the main presenter which thrilled him. Regarding his presentation Simon said, "the people were really nice and I did really good." In fact, the representatives there asked Simon about taking his presentation on the road and offered him opportunities to speak at their facilities. Simon returned even more enthused about training those who work for him.

Legislative Preview

by **Sue Marquardt**

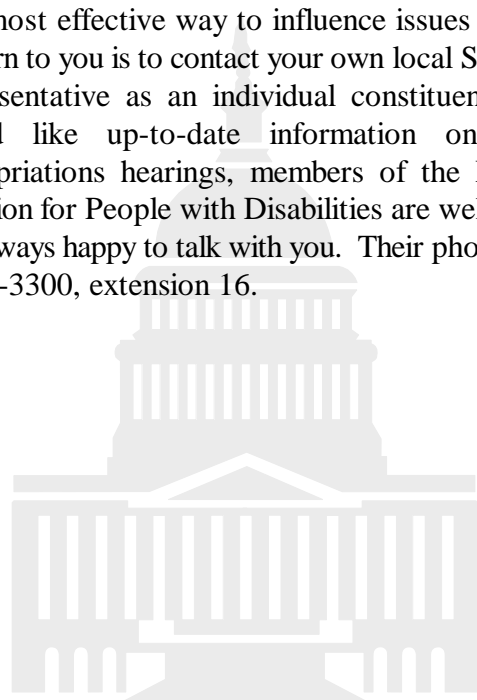
Associate Director

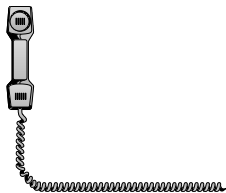
The biggest issue for people with disabilities in the 1999 Legislature will be funding of services. The Governor has recommended \$2 million for the waiting list in his budget. Advocates will be active at the Legislature in support of waiting list funding. The Governor's budget does not include a Cost-of-Living Adjustment (COLA) for providers, but the provider group will be requesting legislators to consider one for them.

There has been an effort made over the last few years to gather information and compile data about the need for more guardianship services in the state. The Department of Human Services is supporting a Guardianship bill which would establish an Office of the Public Guardian to be housed within the Department of Human Services. The intention is to gradually increase the services available to elderly persons and people with disabilities. **Senator Hillyard** will sponsor this bill.

H.B. 31, sponsored by **Representative Judy Ann Buffmire**, will correct a flaw in the existing law on the Tax Credit Form. Currently there is no provision for an entity to certify that a disability exists for individuals age 18 to 22 who are no longer in school. This bill specifies that the Division of Services for People with Disabilities will do it.

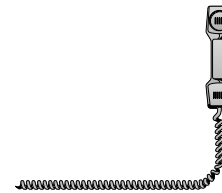
The most effective way to influence issues that are of concern to you is to contact your own local Senator and Representative as an individual constituent. If you would like up-to-date information on bills or appropriations hearings, members of the Legislative Coalition for People with Disabilities are well informed and always happy to talk with you. Their phone number is 363-3300, extension 16.





FAMILY LINES

Family Support in the News



Lacey Gets Her Wish

by **Lacey Heaton**

reprinted from "Real Lives - Successful Stories About Person-Centered Planning



My name is **Lacey Heaton** and I'm twelve years old. I live in Enoch, Utah, and am a student in the sixth grade at Cross Hollows Intermediate School. Like many students what I enjoy most about school is being there with my friends. I also like to spend time with my family, especially my sisters.

I'm pretty much an ordinary kid, but I was born with some challenges that a lot of kids don't have. I have spina bifida, so I have to use a wheelchair in order to get around. Sometimes this is frustrating for me, because it won't go some of the places or go as fast as my friends like to go. That used to mean that I'd get left out a lot.

About a year and a half ago, I was at Primary Children's Medical Center to be refitted for my wheelchair. I was working with the physical therapist when an interesting contraption in the room caught my eye. The physical therapist explained that it was a hand-propelled tricycle, and he asked if I'd like to take it on a test-drive. I jumped at the chance and it was great! I was able to get around just like my friends on their bikes--only I was using my arms to peddle instead of my legs. The bad news was that it was terribly expensive. I left the hospital wishing and dreaming that I could have something like that of my own.

Because of the extra challenges that I have, I have some help to set personal goals. My parents and I, along with some friends meet every so often with a representative from Easter Seals and my Support Coordinator from the Division of Services for People with Disabilities (DSPD). We evaluate and assess progress on my current goals, and set new, future goals. They are called Person-Centered Planning meetings.

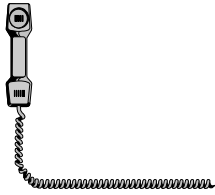
At my last planning meeting, we were talking about some goals I could set to help me socialize better and have better access to the community. We decided to make my last goal to get one of the tricycles like I'd seen at Primary Children's Medical Center. We didn't really think I'd ever get one because it cost so much money, but we made it a goal anyway, just for fun.

About three or four months after my planning meeting, my parents and I got a call from my Support Coordinator, who said he'd been told about some special funds that would be available only one time. He said he'd remembered my wish about the tricycle from the last planning meeting and wondered if we'd like to request the funding to see if we could buy one for me. He felt that having the tricycle would open up "a whole new world" for me. Of course, we said "Yes!", and so he put in the request. He cautioned us not to get our hopes up too high because there would be a lot of other people applying for the money too.

A short time later my Support Coordinator contacted us with great news. Our request for the money had been approved!

The next thing my Support Coordinator did was contact Primary Children's Medical Center. He talked to the physical therapist there, as well as some other friends who work at the hospital. Then he talked to the people at Intermountain Medical, the company that supplies the tricycles. Together they made arrangements for me to meet them so I could be measured for the tricycle. Then we ironed out the details about the cost and which model of tricycle I would get. After all the dreaming, I finally had my tricycle.

My friends in the neighborhood come to my house all the time now. We ride all over the neighborhood. I go most anywhere they go and every bit as fast. I'm out in the community more and am having more fun than ever!



FAMILY LINES

Family Support in the News



Cydnee Goes to College

by Cydnee Rowley

reprinted from "Real" Lives - Successful Stories About Person-Centered Planning

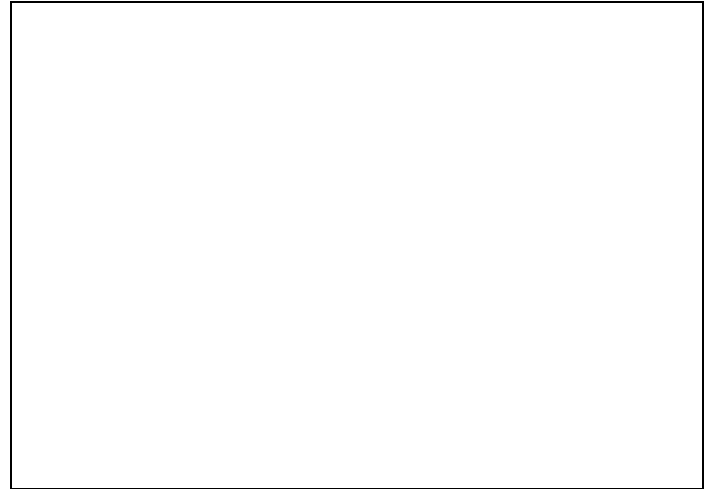
Editor's Note: Cydnee's story was selected as the winner at the Division's November Conference. Prizes included \$100 and a gold clock. She showed how natural supports can expand opportunities and make positive changes in your life. Amber Pierce and Lisa Edwards were also recognized for their affirmative life changes using natural supports.

When I went to Viewmont High School, I decided after graduation I would like to go on a mission for my church. But I was not old enough. So then I decided that I would like to go to college. I wanted to learn more and to listen to my teachers.

My sister, **Heather**, went to college and told me about her classes and stories of how fun college was. My brother, **Chad**, went to college too and he told me how important it was to go to class and to do homework. He had fun too. I knew I would miss my family, but it was something I wanted to do.


I went to Ephraim to visit the campus and I really liked it. **Lorna** (who helped me write my Individual Education Plan) introduced me to **Susie**--she is the roommate that I share a room with. My support coordinator got the money to pay Susie to help me do some things. The rest of the time she's just my roomie. I said what classes I wanted to take and all of those college teachers met with me and everyone else at my planning meeting. The classes I go to are college survival, water body conditioning, choir, band and Institute. **Marcie** (Family Support staff) helps me learn about money, plan my meals and make a shopping list and helps me with my homework. The speech people help me say my words.

College is different than high school. I live in an apartment with nine roommates and not at home. The social life is a lot better and I am very happy here at



Cydnee (2nd from left, top) surrounded by her roommates and family

Snow College. My favorite class is band. I am in the percussion section. I love college and all the activities. I would rather stay at school than go home on the weekends. I like everything about Snow College except having to walk so far between classes, but that is good for me. I also don't like having to get up early for class, especially after a late night hanging out with my roommates. Having nine roommates and living in an apartment complex with lots of close friends and neighbors is good support for me. I like all the boys who live downstairs. Everybody goes to games, concerts, dances and activities. We like to have fun.




Family Matters

A conference for parents of children and adults with disabilities

March 19-20 9:00 a.m. - 5:00 p.m.

Provo Marriott

for more information contact Marilyn Williams 364-5060





Utah Department of Human Services
DIVISION OF SERVICES FOR PEOPLE WITH DISABILITIES
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THIS IS AN
ACRONYMS
FREE WORKPLACE

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MANAGING EDITOR LAYOUT/DESIGN
Sharon Yearsley Helene Lonick

The Division of Services for People with Disabilities is committed to continuous improvements to enhance excellence in our service delivery system.

This Division Promotes

◆ PEOPLE FIRST ◆
LANGUAGE

Upcoming Events

March 19 **Salt Lake City** **11:30 a.m. - 4:30 p.m.**

(½ day workshop - box lunch included)

American Assn. on Mental Retardation Workshop: "Trading Places," by David Hammis from Montana Rural Institute (Supporting Sponsor: Division of Services for People with Disabilities) Workshop will focus on community employment for individuals with significant disabilities and include several innovative, proven and provoking approaches on Resource Ownership, Limited Liability Partnerships, and Businesses within Businesses, Plans for Achieving Self-Support, and State Administered Self-Sufficiency Trusts generating interest payments for long-term Supported Employment follow-along.

Please RSVP to Rian Jensen 944-4245 for cost and meeting location.

March 26 **Vernal, UT**

Self-Determination Conference For more information contact Kathy Forsman at 1-435-789-9336

April 19-20 **The Yarrow Hotel** **Park City, UT**

Organizations for People with Disabilities Conference and NADD Training
Contact Sharon Yearsley (801) 538-4182 or Gina Farrer (801) 374-0119

August 27-28 **Provo Marriott Hotel** **Provo, UT**

Quality of Life Conference - Mark your calendars. More information in future issues.

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